



King's Research Portal

DOI:

[10.1136/bmjopen-2016-013591](https://doi.org/10.1136/bmjopen-2016-013591)

Document Version

Publisher's PDF, also known as Version of record

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Knapp, M., Chua, K-C., Broadbent, M., Chang, C. K., Fernandez, J. L., Milea, D., Romeo, R., Lovestone, S., Spencer, M., Thompson, G., Stewart, R., & Hayes, R. D. (2016). Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: Findings from a large London case register. *BMJ Open*, 6(11), [e013591]. <https://doi.org/10.1136/bmjopen-2016-013591>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

BMJ Open Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register

Martin Knapp,¹ Kia-Chong Chua,² Matthew Broadbent,³ Chin-Kuo Chang,⁴ Jose-Luis Fernandez,¹ Dominique Milea,⁵ Renee Romeo,² Simon Lovestone,⁶ Michael Spencer,⁷ Gwilym Thompson,⁷ Robert Stewart,⁴ Richard D Hayes⁴

To cite: Knapp M, Chua K-C, Broadbent M, *et al*. Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register. *BMJ Open* 2016;**6**:e013591. doi:10.1136/bmjopen-2016-013591

► Prepublication history and additional material is available. To view please visit the journal (<http://dx.doi.org/10.1136/bmjopen-2016-013591>).

MP and K-CC joint first authors.

RS and RDH joint last authors.

Received 23 August 2016
Accepted 15 September 2016



CrossMark

For numbered affiliations see end of article.

Correspondence to:
Martin Knapp;
m.knapp@lse.ac.uk

ABSTRACT

Objectives: To examine links between clinical and other characteristics of people with Alzheimer's disease living in the community, likelihood of care home or hospital admission, and associated costs.

Design: Observational data extracted from clinical records using natural language processing and Hospital Episode Statistics. Statistical analyses examined effects of cognition, physical health, mental health, sociodemographic factors and living circumstances on risk of admission to care home or hospital over 6 months and associated costs, adjusting for repeated observations.

Setting: Catchment area for South London and Maudsley National Health Service Foundation Trust, provider for 1.2 million people in Southeast London.

Participants: Every individual with diagnosis of Alzheimer's disease seen and treated by mental health services in the catchment area, with at least one rating of cognition, not resident in care home at time of assessment (n=3075).

Interventions: Usual treatment.

Main outcome measures: Risk of admission to, and days spent in three settings during 6-month period following routine clinical assessment: care home, mental health inpatient care and general hospital inpatient care.

Results: Predictors of probability of care home or hospital admission and/or associated costs over 6 months include cognition, functional problems, agitation, depression, physical illness, previous hospitalisations, age, gender, ethnicity, living alone and having a partner. Patterns of association differed considerably by destination.

Conclusions: Most people with dementia prefer to remain in their own homes, and funding bodies see this as cheaper than institutionalisation. Better treatment in the community that reduces health and social care needs of Alzheimer's patients would reduce admission rates. Living alone, poor living circumstances and functional problems all raise

Strengths and limitations of this study

- We analysed detailed, electronic clinical records of more than 3000 individuals with Alzheimer's disease using natural language processing to generate some of the data.
- We looked at three institutional destinations separately: care home, general hospital inpatient and mental health inpatient.
- Our analyses controlled for a wide range of patient characteristics as potential confounders, but we were constrained by what was available in the records-derived data set.
- Measures used in routine clinical care may lack precision, which cautions against overinterpretation of findings.
- We did not have comprehensive data on usage of primary or community health or social care services.

admission rates, and so major cuts in social care budgets increase the risk of high-cost admissions which older people do not want. Routinely collected data can be used to reveal local patterns of admission and costs.

INTRODUCTION

Central to any dementia plan or policy framework is the question of how to achieve the best health and quality of life outcomes for people with dementia and their carers, while ensuring that systems of treatment and support make the best use of available resources and are affordable. An important consideration is the balance between care in community and institutional settings. Most people with dementia want to remain living

in their own homes for as long as possible, and delaying care home admission is rated as highly important by carers.¹ Supporting people in the community is also very often a less costly option to the public purse than either residence in a care home or (especially) an inpatient admission.² The need to get the optimal community–institutional balance is especially important given projections of rapidly increasing numbers of people with dementia over the coming decades.³

Of course, inpatient admissions are appropriate in order to meet specific health needs, and care homes can provide high-quality care for people with severe symptoms, but admissions to these settings sometimes stem from potentially avoidable crises in the community.^{4–6} Not surprisingly, admission to care home or hospital has, therefore, also been taken as a pivotal event in technology appraisal models, such as that undertaken for the National Institute for Health and Care Excellence to inform guidance on dementia treatment.⁷

We examine the links between the clinical and other characteristics of people with Alzheimer's disease living in the community—particularly their cognitive function and other needs associated with dementia—and both the likelihood of admission to a care home or hospital within a 6-month period, and the associated costs of those admissions. We employ medical records data for more than 3000 people, representing all Alzheimer's disease patients seen and treated by mental health services in a large catchment area of Southeast London. We use natural language processing to extract some of the data from records, an approach not previously employed with 'real-world' data in this kind of study.

METHODS

Design and participants

Data were extracted from routine care data derived from electronic medical records of the South London and Maudsley National Health Service (NHS) Foundation Trust (SLAM). SLAM provides comprehensive secondary mental healthcare to a catchment area of ~1.2 million residents in four London boroughs (Lambeth, Southwark, Lewisham and Croydon), making it one of the largest mental health providers in Europe. SLAM service provision encompasses all aspects of secondary mental healthcare across all age groups, including inpatient, community, general hospital liaison and forensic services. Fully electronic health records have been used comprehensively across all SLAM services since 2006, importing earlier legacy data, and the Clinical Record Interactive Search (CRIS) system, supported by SLAM's NIHR Biomedical Research Centre for Mental Health, was developed in 2008 to enable researchers to search and retrieve past and current anonymised clinical records within a secured firewall efficiently. There are currently over 250 000 cases represented in the CRIS system providing in-depth information on mental healthcare provision, including dementia assessment and

treatment. The protocol for CRIS is described elsewhere,^{8 9} as are its anonymisation and data governance structures. CRIS was approved as a data set for secondary analysis on this basis by Oxfordshire Research Ethics Committee C (08/H0606/71+5).

The sample for analysis comprised every individual in the CRIS system with a diagnosis of Alzheimer's disease (from structured ICS10 and GATE data) and at least one Mini-Mental State Examination (MMSE) rating, and who was not resident in a care home at the time of MMSE assessment. We also excluded individuals whose first contact was with a liaison team. The MMSE¹⁰ is widely used as a measure of cognitive function in clinical services providing specialist dementia care, and was chosen as the measure of exposure for this analysis. From the date of the first MMSE recorded at the time of dementia diagnosis or up to 90 days beforehand, a 6-month follow-up period ('observation window') was defined and investigated for care home and hospitalisation outcomes. Another 6-month window was started from the next MMSE score after this follow-up period, but MMSE scores falling *within* a given window were ignored. Thus, patients with multiple MMSE scores could contribute several non-overlapping follow-up periods (windows) to the analysis so long as the assessments were more than 6 months apart, and our statistical analyses were planned to explore the impact of repeat observations. It would have been possible to look at longer observation windows, but we decided (pre-analysis) to use 6-month windows as a balance between the need for long enough periods to identify impacts on admission and the potential to have multiple windows linked to different baseline levels of cognitive function and other potential influences.

Data were extracted in November 2012 and any follow-up period overlapping the analysis date was dropped from the analysis.

Measurements

Destination outcome measures were drawn from the mental health record (CRIS) and a data linkage made to UK Hospital Episode Statistics (HES) for all individuals on CRIS. For each relevant MMSE assessment point (ie, starting a 6-month window), we used data from CRIS and HES to measure the number of days spent in each of three settings during the subsequent 6 months: care home, mental health inpatient care and general hospital inpatient care. We also summed these measures to give the number of days in *any* institutional setting during the 6-month window. These four destination outcome measures were used as dependent variables in multivariate analyses.

Care home admissions were ascertained from the mental health record using two techniques. The first was an algorithm linking the address fields in the source record to known addresses of care homes for older people in the catchment area (address fields themselves remaining blinded to researchers as part of the

anonymisation pipeline in CRIS). This was supplemented with a manual search of free-text fields in CRIS over relevant time periods. We excluded care home admissions for respite care (as recorded in CRIS). Once an individual had been admitted to a care home, no further data were collected on care home status, although hospital inpatient admissions data continue to be collected (ie, care home admissions not specified as being for respite care were assumed to be permanent). Inpatient admissions to mental healthcare facilities (all of which are provided for the catchment by SLAM) were obtained from CRIS, while inpatient admissions to general/acute hospitals were obtained from HES. The number of care home days until death (or the end of a 6-month period, whichever occurred first) was used to generate one of the outcome measures. A care home resident subsequently receiving inpatient care will have their care home place kept open for them, and so parallel costs were assumed in these circumstances.

The presence of Alzheimer's disease diagnosis was ascertained from a combination of structured fields of psychiatric diagnosis and data obtained using a natural language processing information extraction application which extracts text associated with diagnostic statements in case notes and correspondence letters, taking into account the linguistic context of relevant terms. We used Generalised Architecture for Text Engineering (GATE; <https://gate.ac.uk/>), an open-source platform for natural language processing to extract relevant data from the non-coded, or narrative data, recorded by healthcare workers and which forms a considerable part of the medical record.¹¹ The performance of this automated approach against manual coding for a subsample (n=123) of patients indicates precision (positive predictive value) of 93% and recall (sensitivity) >99%.¹²

NHS numbers (unique identifiers for UK NHS medical records) for all previous and current SLAM contacts are checked monthly against the national mortality database,¹³ and date of death was thus ascertained from the clinical record and made available for analysis.

Regressors for the analyses were all extracted from coded data held in the electronic medical records (EMRs) using CRIS, each relating to the patient's situation at the start of the 6-month period. These comprised the following sociodemographic measures: age (in years); gender; ethnicity (collated into the following groups: (i) Caribbean, African or other Black; (ii) East Asian or South Asian; (iii) mixed, unknown, or other; (iv) White British or Other White; the last of these was the reference group in the regressions); marital status (married, cohabiting, civil partnership, compared to those with no partner); and living alone (binary variable: yes/no).

Cognition was measured from clinically recorded 30-item MMSE scores, ascertained from structured fields in the clinical record and supplemented by scores recorded in case note and/or correspondence text fields ascertained by a natural language processing

application.^{14 15} Where MMSE assessments were substantially incomplete (denominator scores below 20), these were not included in the analysis; otherwise missing items were coded as successfully completed. We analysed the MMSE score as a continuous measure and also its squared term to test for non-linearity in the association with admission and cost.

The Health of the Nation Outcome Scales (HoNOS) are routinely completed and included in the coded data as a mandatory item in the EMR for all SLAM service users as a component of the national mental health minimum data set. We extract HoNOS subscale scores for: living conditions, activities of daily living (ADL), physical illness/disability, agitated behaviour, depression and relationship problems. Each item is scored on a 5-point scale: not a problem (score 0), minor problem requiring no action (score 1), mild problem but definitely present (score 2), moderately severe problem (score 3) and severe to very severe problem (score 4).^{16–19} We recoded each subscale so as to create two dummy variables for each dimension: one dummy variable for *minor problems* (original HoNOS score of 1 given the value 1; all other original HoNOS scores given the value 0) and the second dummy variable for *significant problems* (original HoNOS scores of 2, 3 or 4 given the value 1; all other original HoNOS scores given the value 0).

We also included two binary variables representing admission or not to mental health inpatient care (coded 0 and 1 respectively), and admission or not to general hospital inpatient care (coded 0 and 1 respectively), during the 12 months preceding the start of the 6-month 'analysis window'. Finally, we included a variable indicating the year in which the data were collected (four binary dummy variables for time periods 2007, 2008, 2009, and 2010 or later; each coded 1 for yes, 0 for no).

Each sociodemographic, accommodation, MMSE, HoNOS and previous admission variable referred to the patient's situation at the *start* of the 6-month window, whereas the dependent variables were indicators of admission and costs of all days in each setting over the subsequent 6 months.

Unit costs

Unit costs were taken from the PSSRU *Health and Social Care Costs* volume (2010/11 prices)²⁰ and represent national averages. Private sector nursing home costs were £103 per person per day, and almost all care home admissions for this sample would have been to private sector facilities offering nursing care. Mental healthcare (older adult) inpatient stays cost £319 per person per day. As there was no figure in the 2011 PSSRU volume for geriatric hospital stay, we uprated the 2008 figure to 2010/2011 prices: £274 per person per day. These unit costs include all accommodation-related and care costs included within facility budgets. It is not possible to attach unit costs that reflect different levels of need within a care home or hospital setting.

In England, hospital inpatient costs fall to the NHS. Costs of care home stays could be covered by the NHS, local authority and (private) self-funders, although we did not know these cost allocations for individuals in our sample. We did not have data on usage of primary or community health or social care services.

Statistical analysis

In summary, our approach was to employ logistic regression to model admission probabilities in the entire sample, and then employ generalised linear models (GLM) to describe the associated costs for the subsample who had these admissions. Relationships between admission probabilities, costs and cognitive impairment were non-linear, so we calculated estimates of the effects for three 'case types' representing mild, moderate and severe cognitive impairment. We now explain why we adopted this approach.

Our analysis strategy anticipated that a high proportion of individuals would have no stays in a care home or inpatient setting during the 6-month window, rendering the cost variables highly right-skewed, and potentially making least squares estimation biased and inefficient.²¹ We therefore employed two-part models (TPM) in the estimation process:²² the first part estimated the probability of institutionalisation during the 6-month window for the entire sample and the second part estimated costs only for those patients who spent time in the institutional setting (ie, with non-zero costs). This TPM strategy allowed inferences about care home or inpatient costs to be augmented with information about probability of service use.²³ Adjusted estimates of average costs were obtained by multiplying the estimated average probability of service use (from the first part) by average costs (from the second part). We used logistic regression models (XTGEE) to estimate probabilities for each destination outcome, and generalised estimating equations (GEE) with log-link and gamma family distribution to estimate costs for those patients incurring non-zero costs, conditional upon use. In both parts, we adjusted for repeated observations, because sample members could have more than one observation 'window'. The exception was the second part for care home admissions because these could not be repeated for the same individual.

For each model, the appropriateness of error distribution assumptions was examined using Park's test²⁴ in line with recommendations in Manning and Mullahy.²⁵ We used gamma, which is a flexible distribution often used for modelling healthcare costs.

To illustrate the impact of cognitive impairment on probability and cost of institutionalisation—given the non-linear relationship between MMSE and expected service use—we selected three MMSE values ('case values') to represent mild dementia (MMSE score of 24), moderate dementia (MMSE of 16) and severe dementia (MMSE of 6), examining other 'case values' in sensitivity analyses (see below). These estimates reflect

average marginal effects (AME) at representative values²⁶ (keeping other characteristics as observed)²⁷ and we also compared costs between these different severity levels. We are not seeking to model disease progression.

The estimates of marginal effects were obtained using the margins command in Stata V.11. Estimates were bootstrapped 10 000 times to obtain CIs. We also bootstrapped the cost difference between case types to help interpret the impact of MMSE on costs.

Sensitivity analysis

We re-estimated the TPMs using GLM rather than GEE (ie, ignoring the fact that there were repeated observations).

Cognitive impairment can lead to other problems, such as with ADLs and depression, and the inclusion of these latter variables in the regression could lead to underestimation of the 'total' underlying effect of cognition on probability of admission and costs. We re-estimated all specifications after omitting the ADL and depression variables to see the effect on the MMSE variable coefficients.

To test whether our findings were sensitive to the MMSE values chosen for severe, moderate and mild cognitive impairment (scores of 6, 16 and 24), we repeated our bootstrapping analyses with a different set of MMSE 'case values' (scores of 9, 16 and 22).

We also calculated marginal effects at means (MEMs) as an alternative to AME,²⁷ again using the margins command in Stata V.11, bootstrapping 10 000 times to obtain CIs.

RESULTS

Sample

Data were available for 3075 patients: two-thirds were women; 82% were of white ethnicity; 8% aged under 70 years and 9% aged over 89 years (at the beginning of the first observation period for each; [table 1](#)). Just over one-third had a partner, and one-quarter of them were living alone. Of MMSE scores at the start of the first 6-month windows, 11% were 0–10 (severe dementia) and 45% were 11–20 (moderate dementia). Approximately half of the sample (52.2%) had significant problems with ADL, and around a third (36.7%) had significant problems with physical illness. Smaller proportions were rated as having significant problems with agitation (15.1%), relationships (14.8%), depression (10.8%) or living conditions (9.5%).

During the 6-month study 'windows' examined, 195 patients received at least one mental health inpatient admission, 1140 had a general hospital admission and 361 had a care home admission. Between them, the 3075 individuals in the sample had 5912 eligible 6-month 'windows' during the study period. There were missing data on one or more variables for 266 (4.5%) of these 'windows', which were dropped from the analysis.

Table 1 Sample characteristics at the beginning of the first 6-month observation period (3075 individuals)

Variables (and missing values for the first observation window)	N individuals (% of non-missing observations)
MMSE score (missing data for 0 individuals)	
0–10	323 (10.5)
11–20	1391 (45.2)
21–30	1361 (44.3)
Age (missing data for 0)	
40–59 years	43 (1.4)
60–69 years	207 (6.7)
70–79 years	1049 (34.1)
80–89 years	1486 (48.3)
90 years or above	289 (9.4)
Gender (missing data for 3)	
Female	2059 (67.0)
Male	1013 (33.0)
Ethnicity (missing data for 0)	
White	2529 (82.2)
Caribbean/African	310 (10.1)
East/South Asian	96 (3.1)
Mixed/unknown	140 (4.6)
Partner (missing data for 0)	
No	1956 (63.6)
Yes	1119 (36.4)
Living alone (missing data for 0)	
No	2277 (74.1)
Yes	798 (26.0)
Living conditions (HoNOS11) (missing data for 214)	
Not a problem	2171 (75.6)
Minor problems only	426 (14.8)
Significant problems	274 (9.5)
ADL (HoNOS10) (missing data for 186)	
Not a problem	651 (22.5)
Minor problems only	729 (25.2)
Significant problems	1509 (52.2)
Physical illness (HoNOS5) (missing data for 186)	
Not a problem	965 (33.4)
Minor problems only	865 (29.9)
Significant problems	1059 (36.7)
Agitated (HoNOS1) (missing data for 181)	
Not a problem	1918 (66.3)
Minor problems only	538 (18.6)
Significant problems	436 (15.1)
Depression (HoNOS7) (missing data for 185)	
Not a problem	1818 (62.9)
Minor problems only	760 (26.3)
Significant problems	312 (10.8)
Relationship problems (HoNOS9) (missing data for 188)	
Not a problem	1877 (65.0)
Minor problems only	582 (20.2)
Significant problems	428 (14.8)

HoNOS, Health of the Nation Outcome Scale; MMSE, Mini-Mental State Examination.

In the total of 5624 included ‘windows’, there were 1474 individuals with 1 ‘window’, 637 with 2 windows, 318 with 3, 183 with 4, 92 with 5, 58 with 6, 22 with 7, 14 with 8, 3 with 9, 4 with 10, 2 with 12 and 2 with 14.

Admission probability and costs

The results of the TPM are shown in [tables 2–5](#). The left-hand side of each table shows the association between the *probability of admission* and cognitive impairment and other explanatory factors. The right-hand side of each table shows the association between *costs* of those admissions and cognitive impairment and other factors. As the models are estimated using a log-link function, model estimates are reported in exponentiated form to aid interpretation. This re-expresses the associations in the first part as ORs. For the second part, the associations are re-expressed as ratios of expected cost, which can be interpreted as the percentage change in estimated costs ($=100 \times [\exp(b) - 1]$) for each unit change in an independent variable.

Model limitations were explored by examining residual plots, which showed no apparent patterns of prediction errors in all but one model. The exception was the model for costs of mental health-related inpatient admissions, for which there appeared to be underprediction at lower levels of cost and overprediction at higher levels, potentially a consequence of the small number of patients with such an admission.

Year

Year of assessment was generally not linked to probability or cost, but there were exceptions: probability of general hospital inpatient admission was significantly higher in 2008 than in other years, and probability of mental health inpatient admission was significantly lower in 2009, 2010 or later compared to earlier years (with 2006 as the reference year throughout).

Previous admissions

Prior experience of general hospital inpatient care and mental health inpatient care were strongly predictive of the probability of admission in the study window, to care homes and mental health inpatient treatment; and previous general hospital inpatient care strongly predicted later general hospital admission. Previous admissions were also associated with general hospital inpatient costs, and previous mental health inpatient care was associated with mental health inpatient costs.

Age and other demographic characteristics

After adjustment, older patients had higher probability of admission to all three settings, and older age was also a predictor of higher general hospital inpatient costs. Males had higher rates of admission to general hospital settings than females, as well as of any institutional admission. Relative to white ethnicity and after adjustment, Caribbean/African ethnicity was associated with a lower probability of care home admission and general hospital inpatient admission, and shorter lengths of stay (shown as costs) in general hospital settings (and overall in institutional settings). Mixed/unknown ethnicity was associated with lower probability of care home admission. East/South Asian ethnicity

Table 2 Two-part model estimates for care home admission

Regressors	Probability of admission in 6 months				Cost of admission over 6 months			
	N=5624				N=361			
	OR	95% CI		p Value	Exp (b)	95% CI		p Value
		Lower bound	Upper bound			Lower bound	Upper bound	
MMSE	1.08	1.00	1.16	0.06	1.00	0.95	1.04	0.90
MMSE (squared)	1.00	0.99	1.00	<0.01	1.00	1.00	1.00	0.96
Year (Ref: 2006 or earlier)								
2007	1.00	0.69	1.46	0.99	0.91	0.75	1.10	0.32
2008	1.27	0.89	1.81	0.18	0.84	0.71	1.01	0.06
2009	1.08	0.75	1.55	0.67	0.97	0.81	1.17	0.78
2010 or later	1.00	0.71	1.41	0.99	1.00	0.85	1.18	0.98
Prior 12m General hospital inpatient care (Ref: No history)	1.54	1.22	1.94	<0.01	0.97	0.86	1.10	0.66
Prior 12m Mental health inpatient care (Ref: No history)	2.59	1.42	4.74	<0.01	1.18	0.94	1.49	0.15
Age	1.04	1.02	1.06	<0.01	1.00	0.99	1.01	0.88
Gender (0=female; 1=male)	1.11	0.85	1.44	0.44	0.99	0.86	1.14	0.90
Ethnicity (Ref: White)								
Caribbean/African	0.57	0.38	0.86	0.01	1.11	0.93	1.33	0.23
East/South Asian	0.57	0.24	1.34	0.20	1.12	0.77	1.64	0.56
Mixed/unknown	0.30	0.12	0.74	0.01	0.83	0.54	1.30	0.42
Partner (Ref: No partner)	0.60	0.45	0.80	<0.01	0.91	0.78	1.05	0.19
Living alone (Ref: Not)	1.29	0.99	1.67	0.06	0.84	0.74	0.97	0.01
Living conditions (HoNOS11)								
Minor problems only	1.59	1.19	2.12	<0.01	0.99	0.87	1.14	0.93
Significant problems	1.65	1.18	2.32	<0.01	1.07	0.91	1.27	0.41
ADL (HoNOS10)								
Minor problems only	1.17	0.72	1.91	0.53	0.90	0.68	1.20	0.49
Significant problems	1.87	1.21	2.90	0.01	0.92	0.71	1.20	0.53
Physical illness (HoNOS5)								
Minor problemsonly	1.10	0.80	1.51	0.58	1.06	0.90	1.25	0.50
Significant problems	1.23	0.91	1.68	0.18	0.98	0.84	1.16	0.84
Agitated (HoNOS1)								
Minor problems only	1.41	1.05	1.89	0.02	1.02	0.88	1.19	0.76
Significant problems	1.98	1.45	2.70	<0.01	1.03	0.89	1.19	0.68
Depression (HoNOS7)								
Minor problemsonly	0.94	0.72	1.24	0.68	1.10	0.96	1.25	0.16
Significant problems	1.13	0.79	1.60	0.51	1.02	0.86	1.20	0.82
Relationship (HoNOS9)								
Minor problems only	1.10	0.82	1.48	0.51	0.98	0.85	1.13	0.78
Significant problems	1.22	0.88	1.69	0.24	0.97	0.82	1.13	0.67
Constant term	<0.01	<0.01	0.01	<0.01	11 356	4272	30 188	<0.01

Reference group for all HoNOS variables: no problem. Exp(b) estimate is the ratio of expected cost, which can be interpreted as the percentage change in estimated costs ($=100 \times [\exp(b) - 1]$) for each unit change in an independent variable.

HoNOS, Health of the Nation Outcome Scale; MMSE, Mini-Mental State Examination.

was also associated with a lower probability of general hospital inpatient admission.

Living situation

Individuals with a partner had a lower probability of admission to care homes and general hospital inpatient settings, but higher probability of mental health inpatient admission, and those living alone had a higher probability of admission to all settings. Considering all three institutional settings, costs were

higher for patients without a partner or living alone, conditional on admission.

Symptoms and needs

Considering HoNOS variables, problems with living conditions were associated with higher probability of admission to each type setting, but did not affect costs except when all settings are grouped together, when costs were significantly higher. ADL problems were associated with care home admission and overall risk of

Table 3 Two-part model estimates for general hospital inpatient admission

Regressors	Probability of admission in 6 months				Cost of admission over 6 months			
	N=5624				N=1140			
	OR	95% CI		p Value	Exp (b)	95% CI		p Value
		Lower bound	Upper bound			Lower bound	Upper bound	
MMSE	0.93	0.88	0.97	<0.01	0.99	0.95	1.03	0.64
MMSE (squared)	1.00	1.00	1.00	0.06	1.00	1.00	1.00	0.98
Year (Ref: 2006 or earlier)								
2007	1.05	0.83	1.33	0.67	1.13	0.90	1.40	0.29
2008	1.33	1.07	1.67	0.01	0.97	0.79	1.20	0.81
2009	1.23	0.98	1.54	0.07	0.93	0.75	1.16	0.53
2010 or later	1.16	0.93	1.43	0.19	1.07	0.87	1.30	0.53
Prior 12m General hospital inpatient care (Ref: No history)	2.21	1.92	2.55	<0.01	1.14	1.00	1.29	0.05
Prior 12m Mental health inpatient care (Ref: No history)	0.83	0.48	1.42	0.49	1.71	1.13	2.58	0.01
Age	1.04	1.02	1.05	<0.01	1.02	1.01	1.03	<0.01
Gender (0=female; 1=male)	1.36	1.16	1.61	<0.01	0.93	0.81	1.08	0.34
Ethnicity (Ref: White)								
Caribbean/African	0.68	0.53	0.88	<0.01	0.68	0.53	0.88	<0.01
East/South Asian	0.43	0.25	0.73	<0.01	0.77	0.52	1.15	0.21
Mixed/unknown	1.35	0.93	1.96	0.11	0.98	0.74	1.31	0.90
Partner (Ref: No partner)	0.77	0.67	0.93	<0.01	0.87	0.74	1.02	0.09
Living alone (Ref: Not)	1.26	1.05	1.49	0.01	1.11	0.95	1.30	0.18
Living conditions (HoNOS11)								
Minor problems only	1.47	1.22	1.79	<0.01	1.13	0.96	1.33	0.16
Significant problems	1.75	1.37	2.22	<0.01	1.12	0.94	1.34	0.22
ADL (HoNOS10)								
Minor problems only	1.15	0.91	1.45	0.25	1.15	0.90	1.46	0.25
Significant problems	1.25	1.00	1.57	0.05	1.18	0.94	1.47	0.15
Physical illness (HoNOS5)								
Minor problems only	1.30	1.07	1.57	<0.01	1.09	0.89	1.34	0.42
Significant problems	2.15	1.78	2.60	<0.01	1.33	1.14	1.63	<0.01
Agitated (HoNOS1)								
Minor problems only	1.11	0.92	1.35	0.27	1.17	1.00	1.38	0.06
Significant problems	1.50	1.21	1.88	<0.01	1.12	0.95	1.33	0.19
Depression (HoNOS7)								
Minor problems only	0.96	0.81	1.14	0.63	0.94	0.81	1.09	0.41
Significant problems	1.49	1.18	1.88	<0.01	1.02	0.84	1.24	0.85
Relationship (HoNOS9)								
Minor problems only	1.01	0.84	1.22	0.91	1.02	0.87	1.19	0.80
Significant problems	0.98	0.78	1.24	0.88	1.06	0.88	1.29	0.54
Constant term	0.01	0.00	0.03	<0.01	980.20	386.06	2488.75	<0.01

Reference group for all HoNOS variables: No problem. Exp(b) estimate is a ratio of expected cost, which can be interpreted as the percentage change in estimated costs ($=100 \times [\exp(b) - 1]$) for each unit change in an independent variable.

HoNOS, Health of the Nation Outcome Scale; MMSE, Mini-Mental State Examination.

institutionalisation, but not with costs, or with the probability or cost of either type of hospital admission. The physical illness score was not associated with care home admission or cost, but was associated with a higher probability of general hospital and mental health inpatient admissions and overall institutionalisation, as well as with higher general inpatient costs. Agitation was associated with higher admission probability into each type of setting, and (overall) with costs. Depression was associated with higher probability of general hospital and

mental health inpatient admissions, but not care home admission, and with higher mental health inpatient and overall costs. Relationship problems were not associated with either admission or costs, apart from a higher probability of mental health inpatient admission.

Cognitive impairment

Cognitive impairment (measured by MMSE and its square term) was a significant predictor of care home admission and general hospital inpatient admission, but

Table 4 Two-part model estimates for mental health inpatient admission

Regressors	Probability of admission in 6 months				Cost of admission over 6 months			
	N=5624				N=195			
	OR	95% CI		p Value	Exp (b)	95% CI		p Value
		Lower bound	Upper bound			Lower bound	Upper bound	
MMSE	0.94	0.86	1.02	0.14	1.01	0.96	1.06	0.84
MMSE (squared)	1.00	1.00	1.00	0.77	1.00	1.00	1.00	0.35
Year (Ref: 2006 or earlier)								
2007	0.86	0.55	1.36	0.52	1.08	0.83	1.40	0.56
2008	0.90	0.58	1.39	0.62	1.24	0.96	1.61	0.11
2009	0.50	0.31	0.83	<0.01	1.35	1.00	1.81	0.05
2010 or later	0.36	0.22	0.58	<0.01	1.35	1.02	1.78	0.04
Prior 12m General hospital inpatient care (Ref: No history)	2.40	1.75	3.29	<0.01	1.12	0.94	1.33	0.22
Prior 12m Mental health inpatient care (Ref: No history)	7.73	4.47	13.34	<0.01	1.75	1.37	2.22	<0.01
Age	0.96	0.94	0.98	<0.01	1.00	0.99	1.01	0.86
Gender (0=female; 1=male)	1.16	0.83	1.63	0.39	1.13	0.92	1.38	0.23
Ethnicity (Ref: White)								
Caribbean/African	0.89	0.54	1.47	0.64	0.97	0.73	1.29	0.84
East/South Asian	1.21	0.53	2.75	0.66	1.42	1.04	1.95	0.03
Mixed/unknown	0.86	0.36	2.09	0.75	1.24	0.72	2.11	0.44
Partner (Ref: No partner)	1.63	1.11	2.39	0.01	0.81	0.66	1.01	0.06
Living alone (Ref: Not)	2.56	1.76	3.71	<0.01	1.08	0.89	1.32	0.44
Living conditions (HoNOS11)								
Minor problems only	1.90	1.28	2.81	<0.01	0.87	0.71	1.08	0.22
Significant problems	2.06	1.32	3.21	<0.01	1.23	0.96	1.59	0.10
ADL (HoNOS10)								
Minor problems only	1.23	0.69	2.19	0.49	1.12	0.77	1.62	0.55
Significant problems	0.97	0.56	1.67	0.91	1.15	0.79	1.70	0.46
Physical illness (HoNOS5)								
Minor problems only	1.76	1.13	2.73	0.01	0.94	0.71	1.25	0.68
Significant problems	1.70	1.10	2.64	0.02	1.13	0.85	1.49	0.40
Agitated (HoNOS1)								
Minor problems only	1.86	1.23	2.82	<0.01	0.70	0.54	0.91	0.01
Significant problems	3.59	2.36	5.45	<0.01	1.04	0.81	1.32	0.77
Depression (HoNOS7)								
Minor problems only	0.92	0.63	1.33	0.65	1.20	0.96	1.50	0.11
Significant problems	2.04	1.35	3.09	<0.01	1.25	1.00	1.56	0.05
Relationship (HoNOS9)								
Minor problems only	1.20	0.80	1.80	0.38	1.06	0.85	1.33	0.57
Significant problems	1.71	1.13	2.60	0.01	0.92	0.73	1.16	0.51
Constant term	0.42	0.07	2.67	0.36	17 397	52.66	57 476	<0.01

Reference group for all HoNOS variables: no problem. Exp(b) estimate is a ratio of expected cost, which can be interpreted as the percentage change in estimated costs ($=100 \times [\exp(b) - 1]$) for each unit change in an independent variable.

HoNOS, Health of the Nation Outcome Scale; MMSE, Mini-Mental State Examination.

not a predictor of mental health inpatient admission. However, MMSE did not predict the *cost* of admission for those admitted to any of the destinations. When looking at all forms of institutional admission together ([table 5](#)), worse cognitive impairment was significantly associated with a higher probability of admission.

[Table 6](#) presents marginal mean probability of service use alongside the marginal mean costs in the 6-month window, using the AME procedure. For instance, the probability of being admitted to a care home within a 6-month window was 10% on average for those with

severe cognitive impairment. In this group, those who were admitted to a care home generated costs averaging £10 172 over 6 months. Combining the two parts of the model, we found that people with severe cognitive impairment who were initially living in the community would be expected to generate costs averaging £1059 over a 6-month period for care home admission. Estimates of these expected average costs indicated a monotonic association with higher levels of cognitive impairment regardless of destination outcome, driven mainly by probability of admission.

Table 5 Two-part model estimates for any institutional admission

Regressors	Probability of admission in 6 mths				Cost of admission over 6 mths			
	N=5624				N=1392			
	OR	95% CI		p Value	Exp (b)	95% CI		p Value
		Lower bound	Upper bound			Lower bound	Upper bound	
MMSE	0.93	0.89	0.97	<0.01	1.01	0.97	1.05	0.56
MMSE (squared)	1.00	1.00	1.00	0.17	1.00	1.00	1.00	0.08
Year (Ref: 2006 or earlier)								
2007	1.08	0.87	1.34	0.49	0.99	0.80	1.21	0.89
2008	1.22	0.99	1.51	0.06	0.97	0.80	1.19	0.76
2009	1.12	0.90	1.38	0.31	0.87	0.71	1.06	0.17
2010 or later	1.03	0.85	1.27	0.74	0.86	0.71	1.05	0.13
Prior 12m General hospital inpatient care (Ref: No history)	2.14	1.87	2.45	<0.01	1.19	1.06	1.35	<0.01
Prior 12m Mental health inpatient care (Ref: No history)	2.15	1.35	3.41	<0.01	2.89	2.30	3.64	<0.01
Age	1.03	1.02	1.04	<0.01	1.00	0.99	1.01	0.52
Gender (0=female; 1=male)	1.31	1.12	1.53	<0.01	0.99	0.86	1.14	0.90
Ethnicity (Ref: White)								
Caribbean/African	0.65	0.51	0.82	<0.01	0.76	0.61	0.95	0.02
East/South Asian	0.56	0.36	0.90	0.01	1.35	0.88	2.07	0.17
Mixed/Unknown	1.07	0.74	1.55	0.71	0.78	0.57	1.08	0.14
Partner (Ref: No partner)	0.79	0.67	0.93	<0.01	0.86	0.74	1.01	0.06
Living alone (Ref: Not)	1.34	1.13	1.58	<0.01	1.20	1.05	1.37	0.01
Living conditions (HoNOS11)								
Minor problems only	1.43	1.19	1.73	<0.01	1.27	1.08	1.49	<0.01
Significant problems	1.89	1.50	2.38	<0.01	1.34	1.13	1.60	<0.01
ADL (HoNOS10)								
Minor problems only	1.16	0.93	1.45	0.18	1.09	0.85	1.41	0.49
Significant problems	1.29	1.05	1.60	0.02	1.10	0.87	1.38	0.42
Physical illness (HoNOS5)								
Minor problems only	1.30	1.09	1.56	<0.01	1.08	0.90	1.29	0.41
Significant problems	2.05	1.56	2.44	<0.01	1.09	0.91	1.29	0.36
Agitated (HoNOS1)								
Minor problems only	1.26	1.06	1.51	0.01	1.13	0.97	1.30	0.11
Significant problems	1.97	1.59	2.42	<0.01	1.54	1.32	1.81	<0.01
Depression (HoNOS7)								
Minor problems only	0.91	0.77	1.07	0.24	1.07	0.92	1.24	0.37
Significant problems	1.52	1.22	1.90	<0.01	1.31	1.09	1.58	<0.01
Relationship (HoNOS9)								
Minor problems only	1.07	0.89	1.27	0.47	1.09	0.94	1.28	0.25
Significant problems	1.10	0.88	1.37	0.40	1.13	0.95	1.33	0.16
Constant term	0.02	0.01	0.06	<0.01	9704.3	4157.3	22 653	<0.01

Reference group for all HoNOS variables: no problem. Exp(b) estimate is a ratio of expected cost, which can be interpreted as the percentage change in estimated costs ($=100 \times [\exp(b) - 1]$) for each unit change in an independent variable.

HoNOS, Health of the Nation Outcome Scale; MMSE, Mini-Mental State Examination.

For care home admission, mean expected costs for people with severe (£1029; 95% CI £773 to £1346) or moderate (£784, 95% CI £666 to £902) cognitive impairment were at least double the costs for those with mild impairment (£325; 95% CI £239 to £411). Bootstrapped estimates (table 7) show that the differences between severity levels are significant.

For general hospital inpatient admission, mean expected costs for people with severe cognitive impairment (£1805; 95% CI £1343 to £2267) were about 1.5 times higher than those with moderate impairment (£1204; 95% CI £1042 to £1367), and almost double the

size when compared to those with mild impairment (£987; 95% CI £837 to £1137). Differences between severity levels were significant (table 7).

Turning to mental health inpatient care, mean expected costs associated with severe cognitive impairment (£1921; 95% CI £1259 to £2583) were three times higher than those with mild impairment (£625; 95% CI £370 to £880). However, CIs were wide for the individual differences between severe and moderate impairment (mean difference: £852; 95% CI £133 to £1570) and between moderate and mild impairment (mean difference: £443; 95% CI £39 to £848).

Table 6 Average costs estimates (average marginal effects (AME))

	AME probability	AME cost	Bootstrapped estimated cost	Bootstrapped 95% CI	
				Lower bound	Upper bound
Care home					
MMSE 6 (severe)	0.10	10,172.23	1059.23	772.89	1345.58
MMSE 16 (moderate)	0.08	9782.47	784.00	665.58	902.42
MMSE 24 (mild)	0.03	9424.14	325.37	239.24	411.49
General hospital inpatient care					
MMSE 6 (severe)	0.29	6313.06	1805.13	1343.35	2266.90
MMSE 16 (moderate)	0.21	5754.21	1204.37	1041.94	1366.80
MMSE 24 (mild)	0.18	5355.17	987.04	836.97	1137.12
Mental health inpatient care					
MMSE 6 (severe)	0.06	32,874.80	1920.58	1258.59	2582.57
MMSE 16 (moderate)	0.04	29,441.30	1068.82	730.66	1406.99
MMSE 24 (mild)	0.03	24,248.87	624.89	370.08	879.71
Any institutional care					
MMSE 6 (severe)	0.37	13,543.53	4948.17	3761.50	6134.84
MMSE 16 (moderate)	0.26	11,946.93	3163.18	2728.28	3598.08
MMSE 24 (mild)	0.22	9230.684	2007.63	1703.81	2311.45

MMSE, Mini-Mental State Examination.

Table 7 Estimated difference between AMEs

	Bootstrapped estimated cost difference	Bootstrapped 95% CI (lower bound)	Bootstrapped 95% CI (upper bound)	p Value
Care home				
MMSE severe versus mild	733.87	424.89	1042.85	<0.001
MMSE severe versus moderate	275.24	-16.49	566.96	0.064
MMSE moderate versus mild	458.63	317.90	599.37	<0.001
General hospital inpatient care				
MMSE severe versus mild	818.09	315.34	1320.83	0.001
MMSE severe versus moderate	600.76	147.04	1054.48	0.009
MMSE moderate versus mild	217.33	7.74	426.92	0.042
Mental health inpatient care				
MMSE severe versus mild	1295.68	506.93	2084.43	0.001
MMSE severe versus moderate	851.76	133.10	1570.42	0.020
MMSE moderate versus mild	443.93	39.93	847.93	0.031
Any care				
MMSE severe versus mild	2940.54	1738.96	4142.12	0.001
MMSE severe versus moderate	1784.99	653.34	2916.63	0.002
MMSE moderate versus mild	1155.55	669.32	1641.79	0.001

AMEs, marginal costs estimates; MMSE, Mini-Mental State Examination.

Combining all destinations into one dependent variable, our estimates show that mean expected costs associated with severe cognitive impairment (£4948; 95% CI £3762 to £6135) were much higher than those with moderate impairment (£3163; 95% CI £2728 to £3598) or mild impairment (£2008; 95% CI £1704 to £2311). Bootstrapped estimates (table 7) suggested that differences between different levels of cognitive impairment were robust.

Sensitivity analysis

Using GLM rather than GEE to estimate the equations did not greatly change the results (see online supplementary appendix tables 1–4).

Excluding the ADL and depression variables from the regressions made very little difference to the coefficient values or significance for the MMSE variables (see online supplementary appendix tables 5–8).

To test whether our findings for the marginal estimates were sensitive to the MMSE scores chosen for our three 'case values', we repeated our analyses with a different set of values (MMSE scores of 9, 16 and 22 for mild, moderate, and severe impairment, respectively). These results led us to the same conclusions regarding cost differences (see online supplementary appendix tables 9 and 10).

We estimated MEMs and compared with our AME estimates. MEM estimates were generally smaller than the AME estimates, but the same substantive conclusions

were reached with either approach (see online supplementary appendix tables 11 and 12).

DISCUSSION

Summary

A theme running through Government policy in England—in the National Dementia Strategy 2009,²⁸ and in the two Prime Minister's Challenge issued in 2012²⁹ and 2015³⁰—has been to emphasise the desirability of people with dementia being able to remain in their own homes for as long as possible. The high per diem costs of institutional settings, combined with a common and understandable reluctance among people with dementia to move from their own homes, make it important that strategic decision-makers and commissioners understand the circumstances under which individuals are at risk of such admissions.

We explored the links between, on the one hand, cognitive function and other characteristics of people with Alzheimer's disease living in community settings and, on the other hand, the probability of admission to care home or inpatient settings, and the associated costs. We used observational data from a large mental health provider in London. The observation period for each study participant was broken into 6-month windows so that assessment data over multiple time-points could better reflect the level of cognitive impairment closer to the time when costs were incurred. The estimation of average costs took into account concomitant influences of physical and mental health, sociodemographic factors and living circumstances.

We found that a range of patient characteristics and living circumstances were independent predictors of the probability of admission to either care home, general inpatient or mental health inpatient settings, and/or the associated costs over the 6-month period. Important predictors included cognition, functional or ADL-related problems, agitation, depression, physical illness, previous hospitalisations, age, gender, ethnicity, living alone, and having a partner. However, patterns of association differed by the type of destination, as discussed below.

Strengths and limitations

A strength of the study was that our large sample was inclusive of all patients diagnosed with Alzheimer's disease on the electronic medical record system of a large mental healthcare service provider that is a near-monopoly provider for its geographical catchment. In the UK, such mental healthcare NHS Trusts are the predominant providers of dementia assessment and specialised healthcare for people with dementia. Our study is unusual in using natural language processing to generate some of the data from clinical records, demonstrating the potential to use real-world data to explore patterns of association in standard services. We looked at three institutional destinations separately: care home, general hospital inpatient and mental health inpatient.

This is important because they not only have different *per diem* costs which fall to different budgets, but also are associated in different ways with patient-level predictors of admission (and cost).

Our analyses controlled for a wide range of patient characteristics as potential confounders, but we were constrained by what was available in the records-derived data set. There may have been residual confounding from covariates not included, such as pharmacological or other treatments, lifestyle choices (eg, alcohol intake, smoking, diet or physical activity) and illness duration. Certain measures, such as those based on HoNOS items, are widely used in routine clinical care but lack measurement precision, and we would caution against overinterpretation; this is a familiar limitation of using 'real-world' data. We could not explore any supply-side influences such as availability of care home places in the catchment, nor did we have data on carer burden, which has been found to be a predictor of nursing home admission.^{4-6 31} We did not look at pharmacological, psychological or other interventions as potential predictors. We did not have an indicator of duration of illness prior to MMSE assessment.

We did not have data on usage of primary or community health or social care services, but we did not set out to study the *comprehensive* costs of supporting people with Alzheimer's disease. Unit costs employed to weight durations of stay are available as national averages for each type of setting, and do not reflect any within-setting differences linked to individual needs or characteristics; this is common to all such work in this area. Costs for care homes are averages across residents with and without dementia, although most UK care homes today have high proportions of residents with dementia.³² We did not have data on the actual length of stay in care home as the administrative data sets recorded only the first instance of care home admission, although very few residents leave a home permanently after admission.³³

Implications for policy and practice

All secondary mental healthcare within the four boroughs that form the SLAM catchment is provided free at the point of use to patients as part of the NHS, but the characteristics of those known to secondary care may still be influenced by levels of disadvantage or referral bias. Consequently, the generalisability of these findings is principally to secondary care rather than primary care populations.

Patterns of prediction were quite different for the three destination outcomes studied, and the implications for policy and practice therefore require individual consideration.

Looking first at *care homes*, the probability of admission was higher for Alzheimer's disease patients with greater severity of cognitive impairment, more severe functional problems and greater agitation. Other predictors of higher probability were general hospital or mental health hospitalisation in the previous 12 months, who

were older, not of Caribbean/African or other Black or unknown ethnicity, who did not have a partner, who lived alone and who had received ratings for poor living conditions. Factors *not* associated with care home admission were physical illness, depression, gender, relationship problems or year in which assessment was carried out. The only significant predictor of care home-related costs was 'living alone', associated with lower costs. Other studies of care/nursing home admissions—for older people in general, or for people with dementia in particular—have found that cognition, ADLs, behavioural problems (including agitation), living alone, older age, poor overall health and prior nursing home use are important predictors.^{4 6 31 34 35}

For *general hospital inpatient stays*, admission probability was higher for patients with more severe cognitive impairment, physical illness, agitation, depression, with a previous general hospital stay in the past 12 months, who were older, female, of White ethnicity, without a partner, living alone and with poor living conditions. Factors *not* associated with general hospital admission were ADL and relationship problems. Costs associated with general hospital inpatient stays during the 6-month window were higher for individuals with physical health problems, a previous hospitalisation in the year before assessment, older age, and not of Caribbean, African or other Black ethnicity.

The probability of *mental health inpatient admission* was higher for patients with physical illness, agitation, depression, with a previous inpatient hospital stay in the past 12 months, who were younger, with a partner, living alone, with poor living conditions, relationship problems and assessed later in the research period. Factors *not* associated with mental health inpatient admission were cognition, ADL problems, gender and ethnicity. Mental health inpatient costs during the 6-month window were higher for individuals with agitation, depression, of East/South Asian ethnicity, with a previous mental health-related hospital stay in the year before assessment and who were assessed later in the research period. Therefore, while admission to mental health inpatient treatment became less common over time (other things being equal), its cost was greater in later years for those people who were admitted. A recent systematic review and meta-analysis found that behavioural problems (including agitation and wandering) and ADLs were associated with higher risk of hospitalisation for people with dementia.³⁶

Cognitive impairment is a significant predictor of care home and general hospital admissions, and of the overall risk of institutionalisation, but—as discussed below—other individual characteristics are also important. Some cost differences are revealed when we look at our selected MMSE 'case values'. For example, care home costs for people with moderate to severe cognitive impairment are double than those for people with mild impairment, although the cost difference was much smaller between moderate and severe impairment.

General hospital inpatient costs for people with severe cognitive impairment were approximately double than those for people with less moderate or mild severity (but there was no cost difference between our moderate and mild 'case values'). In our analyses, the observed costs differences are influenced more by probability of admission than duration of stay, although we are looking at only 6-month periods. Interventions in the community that can slow down the rate of cognitive decline, at least for a short while, such as some medications^{7 37} and cognitive stimulation therapy,³⁸ could help to delay care home and hospital admissions; most people with dementia want to stay in their own homes. This is generally also seen as a lower-cost option than admission,⁵ but this will not always be the case.³⁹ Recognising and finding ways to reduce or manage physical health problems,³⁶ agitation⁴⁰ and depression⁴¹ in Alzheimer's patients could significantly reduce the risk of institutionalisation, which has implications for primary and secondary healthcare.

Problems with ADL are also important predictors of care home admission and overall institutionalisation risk. Deterioration in ADLs could be linked to disease progression itself, but ameliorative action by community-based social care services could also potentially help to postpone care home admission.⁴² Poor living conditions are also a risk factor for institutionalisation, a problem that might be seen as a responsibility of public sector social care or housing services, or that might be addressed by local voluntary agencies. Although almost clichéd, these findings emphasise the need for effective integrated working between a range of health, social care and other services.

Supporting unpaid carers is another strategy with the potential to delay admissions. Although in our data set we do not have measures of carer burden or mental health, we find that Alzheimer's patients living alone have much higher probabilities of admission to all settings, after adjusting for all other covariates, indicating how coresidence with someone else (who may or may not be a carer) is a protective factor against institutional admission.

Implications for future research

A number of recommendations can be drawn for future research, but we will concentrate here on the most important. One of our findings is that destination matters: the transition of someone with dementia from their own home in the community to a care home or inpatient setting is influenced by different individual characteristics—especially their health and functioning—and various living circumstances. Researcher should therefore avoid aggregating different care destinations when looking at, for example, the risk of institutionalisation.

There is also a need to look not just at cognition but at a range of other symptoms (such as agitation, depression and physical health) and needs (such as independence in ADL) in order to get a fuller understanding of what factors influence pathways and costs of care for Alzheimer's disease patients.

Our study shows that it is now possible to model service patterns and care pathways from real-world data derived from context-appropriate systems in the UK. This would make it possible in future to examine the potential impact on costs of modifying the cognitive trajectory of dementia—or indeed other symptoms—with either disease-modifying or symptomatic therapies. Using real-world data in such models might have considerable benefits compared to other approaches using modelling from data derived from clinical trials which are typically short in length and where the trials participants may not be entirely typical of the population in the community.

The use of real-world data using a combination of pseudonymised extracts of coded and non-coded data and the derivation of information from the non-coded or narrative data in clinical records using natural language processing raises the prospect of very significantly increasing not only the ecological validity but also the scale of data sets used in analyses of care pathways, service use patterns, costs and outcomes.

This study employed data derived from an information system of a large, mental healthcare provider in the UK. As electronic medical records become increasingly universal, as indeed they already are in mental healthcare in the UK, then it will become possible to derive data from *multiple* providers, allowing not only studies at scale but also the prospect of comparison across providers and geographical areas. This has international relevance, of course, even though the structural characteristics, funding arrangements and associated incentives in different health and care systems often lead to different patterns of service usage and costs.³⁹

CONCLUSION

Most people with dementia would like to remain in their own homes for as long as possible, rather than move into a care home or inpatient setting. This is usually the preference of family members too, although the responsibilities of being a carer can become very burdensome as dementia becomes more severe, particularly for spouse carers who will often also have to cope with their own healthcare needs. Community-based care is also seen as a lower-cost option than care home residence (and much cheaper than a protracted inpatient stay), and is therefore encouraged by governments or other health and social care funders concerned about the current and future affordability of dementia care.

With the help of data from the clinical records of a large mental health provider—extracted using novel techniques to generate rich information on each of more than 3000 patients with Alzheimer's disease—we showed that the risks of admission to a care home, general hospital or mental health inpatient care are driven by a number of patient characteristics and living circumstances. We were also able to examine the patient and other factors associated with care home and

inpatient costs. A number of factors were found to be significant, although different combinations of factors influenced the different destination outcomes.

Patient health measures of relevance were cognition, agitation, depression and physical illness, and abilities in ADLs were important in understanding care home admissions. Treatment or care that can reduce these health and social care needs could potentially reduce rates of admission. The effect of older age on admission varied according to destination, having a positive effect on care home and general hospital admission, but a negative effect on mental health inpatient care. The effect of having a partner was also different: it reduced the likelihood of care home and general hospital admission, but *increased* the likelihood of mental health inpatient care. Living alone was a risk factor for all types of admission, and as the UK population ages the number of people living alone demography of the UK changes, with more people living into old age and a high proportion living alone, so the demand for institutional placements could increase.

Those patients who had been admitted as an inpatient in the previous 12 months had a higher probability of subsequent admission to all three of the destinations we studied here. Whether anything can be carried out at hospital discharge to reduce future risks is beyond the scope of this paper. We also found differences in admission patterns between ethnic groups.

Poor living conditions were also shown to be a risk factor for all three destination outcomes, but major cutbacks in public expenditure on social care in England in recent years have made it increasingly difficult for local authorities to provide preventative services in the community. These cutbacks could in time put further pressure on high-cost residential and inpatient services.

Author affiliations

¹Personal Social Services Research Unit, London School of Economics and Political Science, London, UK

²Health Services and Population Research Department, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

³South London and Maudsley National Health Service Foundation Trust, London, UK

⁴Psychological Medicine Department, King's College London, Institute of Psychiatry, Psychology and Neuroscience, London, UK

⁵Lundbeck Singapore PTE Ltd, Singapore, Singapore

⁶Department of Psychiatry, University of Oxford, Oxford, UK

⁷Janssen-Cilag Ltd, High Wycombe, UK

Contributors All the authors listed have made substantial contributions to the preparation of this paper. RS, SL and MK, with input from DM, MS and GT, designed the study. MB designed and carried out the data extraction and processing. C-KC, RDH, MK, RR, K-CC and J-LF designed the data analysis strategy and K-CC conducted the statistical analyses. MK wrote the first draft of the manuscript and led subsequent redrafting; all authors commented on each draft of the manuscript. Each author has given final approval to the manuscript. The corresponding author had access to all data and had complete freedom to direct the analysis and reporting without influence, editorial direction or censorship from the sponsors. The authors thank the reviewers for their helpful comments on an earlier version of this paper.

Funding This study was supported by the Clinical Records Interactive Search (CRIS) system funded and developed by the National Institute for Health

Research (NIHR) Mental Health Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London and a joint infrastructure grant from Guy's and St Thomas' Charity and the Maudsley Charity. We appreciated the technical support from informatics personnel in the Biomedical Research Centre. The analyses were specifically funded by a pre-competitive consortium between King's College London, Pfizer, J&J and Lundbeck. RH is funded by a Medical Research Council (MRC) Population Health Scientist Fellowship. RS, C-KC and MB receive salary support from the NIHR Mental Health Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London. K-CC and RR receive salary support from King's College London. MK and J-LF receive salary support from the London School of Economics and Political Science. DM receives salary support from Lundbeck. MS receives salary support from Janssen-Cilag Ltd. GT receives salary support from Janssen. The views expressed are those of the author, and not necessarily those of the NHS, the NIHR, the Department of Health or any of the organisations employing the authors.

Competing interests RH, C-KC, MB and RS have received research funding from Roche, Pfizer, J&J and Lundbeck; MK has received research or consultancy funding from Roche, Pfizer, J&J, Lundbeck and Takeda; DM is a full-time employee of Lundbeck; GT is a full-time employee of J&J; MS is a full-time employee of Janssen-Cilag Ltd. Other authors have no conflicts to report. The work described in this paper originated from a grant, formed from a pre-competitive consortium between King's College London and three companies (Pfizer, Lundbeck, J&J). The products manufactured by the consortium partners were not analysed as covariates in the study.

Ethics approval The SLAM case register was approved as a data resource for secondary analysis by Oxford C Research Ethics Committee (Ref: 08/H0606/71+5) and all CRIS projects are reviewed and approved by a patient-led Oversight Committee reporting to the SLAM Caldicott Guardian.

Disclaimer MK affirms that the manuscript is an honest, accurate and transparent account of the study being reported. No important aspects of the study have been omitted. Any discrepancies from the study as planned have been explained.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Data from the SLAM case register are required to remain within the SLAM NHS firewall and access is governed by its research ethics approval; however, within these constraints, data can be made available on request and application.

Open Access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

REFERENCES

- Karlawish JH, Klocinski JL, Merz J, *et al.* Caregivers' preferences for the treatment of patients with Alzheimer's disease. *Neurology* 2000;55:1008–14.
- Knapp M, Comas-Herrera A, Wittenberg R, *et al.* Scenarios of dementia care: what are the impacts on cost and quality of life? Discussion Paper 2878. PSSRU, London School of Economics and Political Science, 2014.
- Prince M, Knapp M, Guerchet M, *et al.* *Dementia UK*. 2nd edn. London: Alzheimer's Society, 2014.
- Luppa M, Luck T, Weyerer S, *et al.* Prediction of institutionalization in the elderly. A systematic review. *Age Ageing* 2010;39:31–8.
- National Audit Office. Improving services and support for people with dementia. National Audit Office, 2007.
- Yaffe K, Fox P, Newcomer R, *et al.* Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA* 2002;287:2090–7.
- Bond M, Rogers G, Peters J, *et al.* The effectiveness and cost-effectiveness of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (review of Technology Appraisal No. 111): a systematic review and economic model. *Health Technol Assess* 2012;16:1–470.
- Fernandes AC, Cloete D, Broadbent MT, *et al.* Development and evaluation of a de-identification procedure for a case register sourced from mental health electronic records. *BMC Med Inform Decis Mak* 2013;13:71.
- Stewart R, Soremekun M, Perera G, *et al.* The South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLAM BRC) case register: development and descriptive data. *BMC Psychiatry* 2009;9:51.
- Folstein MF, Folstein SE, McHugh PR. Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189–98.
- Cunningham H, Tablan V, Roberts A, *et al.* Getting more out of biomedical documents with GATE's full lifecycle open source text analytics. *PLoS Comput Biol* 2013;9:e1002854.
- Sultana J, Chang CK, Hayes RD, *et al.* Associations between risk of mortality and atypical antipsychotic use in vascular dementia: a clinical cohort study. *Int J Geriatr Psychiatry* 2014;29:1249–54.
- Chang CK, Hayes RD, Broadbent M, *et al.* All-cause mortality among people with serious mental illness (SMI), substance use disorders, and depressive disorders in southeast London: a cohort study. *BMC Psychiatry* 2010;10:77.
- Perera G, Khondoker M, Broadbent M, *et al.* Factors associated with response to acetylcholinesterase inhibition in dementia: a cohort study from a secondary mental health case register in London. *PLoS ONE* 2014;9:e109484.
- Perera G, Broadbent M, Callard F, *et al.* Cohort profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLAM BRC) Case Register: current status and recent enhancement of an Electronic Mental Health Record derived data resource. *BMJ Open* 2016;6:e008721.
- Wing JK, Beevor AS, Curtis RH. Health of the Nation Outcome Scales (HoNOS). Research and development. *Br J Psychiatry* 1998;172:11–18.
- Orrell M, Yard P, Handysides J, *et al.* Validity and reliability of the health of the nation outcome scales in psychiatric patients in the community. *Br J Psychiatry* 1999;174:409–12.
- Pirkis JE, Burgess PM, Kirk PK, *et al.* A review of the psychometric properties of the Health of the Nation Outcome Scales (HoNOS) family of measures. *Health Qual Life Outcomes* 2005;3:76.
- Hunter R, Cameron R, Norrie J. Using patient-reported outcomes in schizophrenia: the Scottish Schizophrenia Outcomes Study. *Psychiatr Serv* 2009;60:240–5.
- Curtis L. Unit Costs of Health and Social Care 2011: Personal Social Services Research Unit, 2011. <http://www.pssru.ac.uk/project-pages/unit-costs/2011/>
- Buntin MB, Zaslavsky AM. Too much ado about two-part models and transformation? Comparing methods of modeling Medicare expenditures. *J Health Econ* 2004;23:525–42.
- Manning WG, Morris CN, Newhouse JP, *et al.* A two-part model of the demand for medical care: preliminary results from the Health Insurance Study. In: van der Gaag J, Perlman M, eds. *Health, economics and health economics*. Amsterdam: North-Holland, 1981:103–23.
- Mullahy J. Much ado about two: reconsidering retransformation and the two-part model in health econometrics. *J Health Econ* 1998;17:247–81.
- Park RE. Estimation with heteroscedastic error terms. *Econometrica* 1966;34:888.
- Manning WG, Mullahy J. Estimating log models: to transform or not to transform? *J Health Econ* 2001;20:461–94.
- Cameron A, Trivedi P. *Nonlinear regression methods. Microeconometrics Using Stata*. 2nd rev edn. Stata Press, 2010.
- Bartus T. Estimation of marginal effects using margeff. *Stata J* 2005;5:309–29.
- Department of Health. Living Well With Dementia: a national dementia strategy London, UK: Department of Health, 2009. <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>
- Department of Health. Prime Minister's challenge on dementia - Delivering major improvements in dementia care and research by 2015 London, UK: Department of Health, 2012. <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia>
- Department of Health. Prime Minister's challenge on dementia 2020 London, UK: Department of Health, 2015. <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia>
- Hebert R, Dubois MF, Wolfson C, *et al.* Factors associated with long-term institutionalization of older people with dementia: data from the Canadian Study of Health and Aging. *J Gerontol A Med Sci* 2001;56:M693–M99.

32. Stewart R, Hotopf M, Dewey M, *et al.* Current prevalence of dementia, depression and behavioural problems in the older adult care home sector: the South East London Care Home Survey. *Age Ageing* 2014;43:562–7.
33. Netten A, Darton R, Bebbington A, *et al.* Residential and nursing home care of elderly people with cognitive impairment: prevalence, mortality and costs. *Aging Ment Health* 2001;5:14–22.
34. Gaugler JE, Duval S, Anderson KA, *et al.* Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatr* 2007;7:13.
35. Howard R, McShane R, Lindesay J, *et al.* Nursing home placement in the Donepezil and Memantine in Moderate to Severe Alzheimer's Disease (DOMINO-AD) trial: secondary and post-hoc analyses. *Lancet Neurol* 2015;14:1171–81.
36. Toot S, Devine M, Akporobaro A, *et al.* Causes of hospital admission for people with dementia: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2013;14:463–70.
37. Howard R, McShane R, Lindesay J, *et al.* Donepezil and memantine for moderate-to-severe Alzheimer's disease. *N Engl J Med* 2012;366:893–903.
38. Orrell M, Aguirre E, Spector A, *et al.* Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *Br J Psychiatry* 2014;204: 454–61.
39. Wübker A, Zwakhalen SM, Challis D, *et al.* Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. *Eur J Health Econ* 2015;16:689–707.
40. Livingston G, Kelly L, Lewis-Holmes E, *et al.* A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia. *Health Technol Assess* 2014;18:1–226.
41. Romeo R, Knapp M, Hellier J, *et al.* Cost-effectiveness analyses for mirtazapine and sertraline in dementia: randomised controlled trial. *Br J Psychiatry* 2013;202:121–8.
42. Davies B, Fernández J-L. The contribution of community-based health and social care to inpatient hospital use London, UK: LSE Health and Social Care, London School of Economics and Political Science, 2005. <http://eprints.lse.ac.uk/13840/>

Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register

Martin Knapp, Kia-Chong Chua, Matthew Broadbent, Chin-Kuo Chang, Jose-Luis Fernandez, Dominique Milea, Renee Romeo, Simon Lovestone, Michael Spencer, Gwilym Thompson, Robert Stewart and Richard D Hayes

BMJ Open 2016 6:

doi: 10.1136/bmjopen-2016-013591

Updated information and services can be found at:
<http://bmjopen.bmj.com/content/6/11/e013591>

These include:

References

This article cites 32 articles, 8 of which you can access for free at:
<http://bmjopen.bmj.com/content/6/11/e013591#BIBL>

Open Access

This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

Email alerting service

Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Topic Collections

Articles on similar topics can be found in the following collections

[Geriatric medicine](#) (242)
[Health economics](#) (292)
[Health policy](#) (571)
[Mental health](#) (588)

Notes

To request permissions go to:
<http://group.bmj.com/group/rights-licensing/permissions>

To order reprints go to:
<http://journals.bmj.com/cgi/reprintform>

To subscribe to BMJ go to:
<http://group.bmj.com/subscribe/>